

Governor's Autism Council

Thursday, May 23, 2013
10:00 AM to 3:00 PM
Risser Justice Center
17 West Main Street & 120 Martin Luther King Jr. Blvd., Room 144
Madison, WI 53701

MEETING MINUTES

Council Members: Nissan Bar-Lev, Wendy Coomer, Vivian Hazell, Nan Huai (for Glen Sallows), Milana Millan, Pam Stoika
Facilitator: Kris Freundlich
DHS Staff: Julie Bryda, Sue Larsen, Meghan Mitchell, Bill Murray

The meeting started at 10:03 AM.

Public comments: There were no members of the public present.

1. Welcome and Introductions

- Council Discussion:
 - Concern was expressed regarding the proposed waitlist update which would allow younger children to be prioritized in order to receive services more quickly. Some members believe prioritizing these children would negatively impact other children with autism and that this decision should not be based on age criteria alone.
 - Other members relayed concern about the length of the waiting list for children who are diagnosed at a later age (e.g., 4 years and older). These children receive treatment at an age when the treatment is not as effective. In addition to the waiting list, additional time is added to this wait for diagnostic testing prior to the child receiving treatment.
- Kris Freundlich reviewed the Council's purpose and some general meeting principles. These included focusing the conversation on ideological discussions and encouraging people to participate in a thoughtful dialogue that leads to action.

2. Approval of Autism Council Meeting Minutes

- Nissan Bar-Lev made a motion to approve the April 11, 2013, meeting minutes; Vivian Hazell seconded the motion and the motion carried.

3. Autism Treatment: Home and School Realities

- The Council held a broad discussion related to the challenges of serving school-aged children who require a high number of treatment hours. The discussion included the following points:
 - The creation of the Consultative Behavioral Intervention (CBI) model can be beneficial for those children and families who struggle to meet the requirements of the Early Intensive Behavioral Intervention (EIBI) model.
 - With the CBI model, some providers are setting aside hours for staffing and travel, and for these children the maximum number of face-to-face treatment may only be as high as 14 to 16 hours per week. Some children may benefit from this level of treatment; however, considering the length of the waiting list, it is felt many of the children need intensive (EIBI) treatment once their funding is available.

- Pam Stoika stated that Integrated Development Services, Inc. (IDS) offers the CBI model only in clinic. This model allows the provider to capitalize on hours of treatment and spend fewer hours on travel. Because many children are only available after school, it is challenging for senior staff to meet with school-aged children. She relayed in their experience, it is not profitable when a senior staff meets with a school-age child.
 - The Department's data indicates many children under the former Intensive In-Home treatment model (20-35 hours per week) often received less than 20 hours per week of face-to-face treatment and providers were using as many as 15 hours per week for travel expenses. There were concerns with this model because some children's weekly hours were regularly billed as administrative costs more so than treatment hours.
 - Prior to implementation of the EIBI and CBI models, the Department carefully considered provider costs, family concerns, Autism Council input, and treatment effectiveness when creating this service.
 - It is acknowledged that while many children benefit from an intensive level of treatment, there remain some children who do not make significant progress at this level.
- State and federal policy limits children from receiving treatment within the school setting while the child is supposed to be receiving an education. The Department of Public Instruction (DPI) is evaluating this issue and is researching other state models to assess if/how they allow for treatment within the school setting. It was felt this concern may best be addressed through a discussion with DPI's legal counsel. If a meeting is arranged, the following questions should be addressed:
 - Is there a possibility to shorten school days for children with mental health concerns?
 - If it is not possible, then could the educational plan include treatment?
 - Is early access to autism treatment needed to ensure educational success?
 - Can the child be assessed holistically when considering what is in their best interest?
 - How is autism therapy different than occupational therapy, speech therapy, and physical therapy when it occurs in the school setting?
 - Is a need for treatment ever prioritized over educational needs?
 - The challenge of finding providers in rural areas was noted, and regardless of the area of the state, meeting required treatment hours is a challenge. Having fewer hours makes it more difficult to maintain staffing because they have fewer hours of work allowed.
 - It was suggested that it is important to evaluate why children are not receiving the number of hours needed for treatment. Generally families want many hours for younger children, but as the child ages, the amount of hours they desire decreases because of other family obligations and activities.
 - The Council noted that autism treatment is a time limited intervention and there should be a way for this treatment to complement the child's education and not be adversarial. Medically necessary interventions are often prioritized over educational policies; however, the same priority is often not given to mental health illnesses or treatments that improve quality of life. Often autism treatment is considered a "quality of life" improvement, but in reality the brain is not functioning properly and this diagnosis should be considered a medical condition.
 - Previous DHS policy permitted for allowing 25 percent (25%) of treatment to occur in a school setting for transitional periods. DPI has clarified that if treatment is being provided at the school, the school should have this treatment listed on the Individualized Educational Program (IEP) and then DPI is responsible for the implementation. More clearly, as the Children's Long-Term Support (CLTS) Waiver must not be used to supplant federal Individuals with Disabilities Education Act (IDEA) requirements, it cannot pay for treatment in school if the school identifies this treatment as necessary. It was noted that some schools are not as well equipped to provide autism treatment.

- Within recent years, schools have substantially improved the number of paraprofessionals and teachers who have an orientation to autism treatment, although factors exist that impact the effectiveness of treatment children receive during the school day, including:
 - An environment that can be quite distracting.
 - Varied roles educators required to serve.
 - The need children with autism have for a one-on-one learning environment which the school setting is not always designed to provide.
- *Universal Design for Learning:*
 - Nissan Bar-Lev informed the Council of a new educational initiative, Universal Design for Learning (UDL). UDL is a set of principles for curriculum development that give all individuals equal opportunities to learn, and it provides a blueprint for creating instructional goals, methods, materials, and assessments that work for everyone.
 - UDL was piloted in Maryland and children's scores are substantially improving because of this model. The WI Department of Public Instruction (DPI) is hosting a presentation with the developers in July, and Nissan will share additional information as it becomes available

4. Autism Wait List

- The CLTS Waiver can provide funding for autism treatment for eligible children who are diagnosed at an early age; however the Council pointed out the research shows treatment is not as effective for children who are over the age of 5 years. The Council discussed whether it was advantageous to update their prior proposal with research supporting the effectiveness of treatment for the youngest children.
- As of May 23, 2013, there are 37 children under the age of 3 years on the Autism wait list. DHS fiscal staff are currently analyzing if the Department has the ability to fund those children if they were taken off the wait list at once (e.g., over the course of a week). It is believed that older children on the wait list will not be negatively impacted by such a proposed action.
- There are 157 children under the age of 4 years and the fiscal analysis indicated that DHS could not fund treatment for all of those children, nor is there a belief providers would have the capacity to serve this many additional children in an already stressed system.
- Milana Millan shared that the Autism Society of Wisconsin is opposed to fast-tracking children who are younger, as they believe it will negatively impact other children.
- Pam Stoika sent out an email to all of the Wisconsin autism providers and asked for their feedback regarding the wait list proposal. Several of the comments referred to children who have private insurance and only access the waiver for a small portion of funding. Another comment suggested creating two separate waiting lists, one for children with insurance and the other for children without insurance; the Council determined this suggestion is not feasible since private insurance can easily change.
- The Council will follow-up on today's dialogue and formulate the basis for the next draft of the proposal. They will also make clear in the proposal that this is an interim change until a larger solution is determined.

Evaluating Treatment Progress

- The Council and Department discussed realities of children receiving treatment and the progress that is made over time. Currently, progress related to treatment is not monitored by the DHS. The provider and the county waiver agency must evaluate progress at set intervals after treatment starts. Typically after twelve months of treatment, if the treatment is not positively impacting the child then DHS and

the county waiver agency need to determine if this treatment is effective. An additional factor is that some families choose not to be involved in treatment, potentially hindering progress, which is against waiver policy.

- Evaluating progress and the impact of family involvement would rely heavily on the work of providers; however, the difference between clinical assessments of progress and family assessments of progress is much different, as family members may often notice marginal progressions. Evaluating progress is a challenge in those cases where children have family who are not involved with treatment, and the child may be benefitting from the intervention.
- The Council relayed that some children make very slow improvements, which can take over two years. Qualitative benefits are demonstrated though the benefits cannot be quantitatively determined. A question that naturally arises is, “At what rate is progress to be expected and in what time frame?” Providers noted it would be challenging to tell a family that their child is not progressing, although using a concrete assessment of progress would be an objective measure. Within many county waiver agencies, the benefits of waiver-funded services are frequently evaluated and if the child is not making progress, the child often does not continue with that service. There are standardized assessment tools that autism providers can use to evaluate a child’s progress. These tools include intelligence testing, the ABLIS (Assessment of Basic Language and Learning Skills), and some providers have used the ADOS (Autism Diagnostic Observation Scale). Although there are means to measure children’s progress that hold providers accountable, there is no current way to measure the involvement of families.

5. DLTC/BLTS Updates

- Sue Larsen provided the following Division and Bureau updates:
 - The Department is collaborating with the Department of Public Instruction (DPI) and Department Workforce Development’s Division of Vocational Rehabilitation (DVR) for a statewide summit designed to educate staff and service coordinators on techniques for children transitioning to adult services.
 - A quarterly data report of all Children’s Services Section program information is under development for internal and external stakeholders. This report will include statistics on: program enrollment, new applications, discontinuations, fair hearing requests, wait list data, and Third Party Administration (TPA) claims data.
 - Division of Long Term Care has hired a new administrator, Brian Shoup. Brian was previously the Director of Brown County Human Services Department, and has a background in mental health services.

6. Meeting Adjournment

- The meeting was adjourned at 2:59 PM.